

STATISTICAL STUDY TO INVESTIGATE WOMEN'S PREFERENCE IN THE PHRASEOLOGY OF LIFETIME AND AGE SPECIFIC RISK OF DEVELOPING BREAST CANCER

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Abstract - There has been a marked increase in the number of requests to image women with a family history of breast cancer in the UK. A postal evaluation form is used to assess risk and to reassure women. However, uncertainty exists about the most appropriate wording of risk information. The aim of this study was to investigate women's preference in the phraseology of lifetime and age specific risk of developing breast cancer.

A sample of 175 women was recruited from 6 geographical regions within the UK. Each woman was asked to state her preference between positive and negative wording of the lifetime risk, and between three alternate ways of phrasing age specific risk (Percentage, Ratio and Description). Women were randomly assigned to six different combinations of wording, with stratification by two age bands: 17-30 and 31-55 years. Data were collected through self-completed, postal questionnaires and responses were received from 137 out of 175 distributed questionnaires. Respondents had a median age of 42 years; 94% had formal educational qualifications; 98% were white European; 68% were married or living with a partner; and 85% were in paid employment (full time or part time). Statistically significantly more women preferred the positive phrasing of lifetime risk (76%) compared with negative wording (24%; $\chi^2=36.57$, $p<0.0005$). With respect to age specific risk, 44%, 19% and 37% of women preferred the Odds, Percentage and Description wording, respectively. A significantly lower proportion of women preferred the Percentage option ($\chi^2=12.82$, $p=0.002$).

The choice of phraseology in the information given to women should focus on positive wording.

Keywords - Cancer screening, family history, inherited cancer

I. INTRODUCTION

Over the last twelve years, much psychological and clinical research has been aimed at predicting attendance and psychological well being amongst the target screening population of women aged 50 years and over. The situation of asymptomatic women has largely been ignored. Recently, women who perceive themselves to have a family history of breast cancer are being seen more frequently in secondary breast care services across the United Kingdom [1]. The referral guidelines for family histories of breast cancer are [2]:

- 1st degree relative (i.e. mother, sister) younger than 40;
- 2nd degree paternal (i.e. fathers parents, aunts) relative younger than 40;
- Two 1st or 2nd degree relatives (or 1 of each) younger than 60;

- 1st degree relative with cancer in both breasts younger than 60;
- 1st or 2nd degree relative with both breast and ovarian cancer younger than 60;
- Three or more close relatives on same side of family of any age;
- 1st degree male relative of any age.

In 1992 the Warwickshire Solihull and Coventry Breast Screening Service, in association with the West Midlands Clinical Genetics Service, set up a family history unit at the University Hospitals of Coventry and Warwickshire NHS Trust. The purpose of such a unit was to rationalise and triage increasing numbers of referrals to both the screening and genetics services. During its first year, two referrals were received; by 1998, the unit was receiving an average of fourteen referrals a month. Of the 130-170 referrals per annum, 35% do not complete the paper work, 42% can be reassured by letter and the remaining 23% require a consultation. Of the latter, 35% are screened, 55% are not screened and 10% are referred for genetics assessment. Women visiting the family clinic at the University Hospitals of Coventry & Warwickshire NHS Trust, Coventry, are required to complete a family history tree prior to an appointment. Where appropriate, this information is validated by a clinical genetics team using the national cancer registry. This ensures that all relevant patient history is correct and allows an accurate collection of individual risk using an adaptation of the Claus model [3]. This model assumes that susceptibility to breast cancer and age at onset of disease are both regulated by the same single diallelic locus.

This rise in referral numbers is not driven by increasing numbers of women with genetic predisposition, but by lack of understanding and anxiety [4]. The initial visit to the general practitioner is believed to be triggered by a lack of understanding regarding individual risk of developing breast cancer. During such consultations, women cite personal risk of developing breast cancer as their main reason for requesting a referral to a secondary care service. Other reasons commonly given include family history of disease, risk to the family, wanting reassurance, requesting genetic testing and disease prevention [5]. The vast majority of referrals to secondary breast care services are suggested by the general practitioner, who may have concerns about an aspect of their patient's family history or the level of anxiety demonstrated by the woman. There is, however, an increasing number of women who present at their general practice

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requesting referral to secondary breast care services for the purpose of receiving genetic testing for the BRCA mutations [5].

A family history of cancer has been shown to increase perceived risk [6] and may be derived from a cognitive bias whereby highly salient events are more easily retrieved from memory and are perceived to be more likely to occur. Dispositional anxiety, hypochondriasis, low self-esteem and a hypervigilant style of information processing, referred to as monitoring [7], have been associated with the development of vulnerability beliefs [8, 9]. Thus, a process of sensitisation due to psychological and social factors, combined with a lack of understanding, may lead to increased perception of risk of breast cancer in asymptomatic women with a family history of the disease. Hence perceived risk is not necessarily correlated with actual risk [10].

Mis-reporting the discovery of the breast cancer susceptibility genes BRCA-1 and BRCA-2 by the media and health professions has further raised concern amongst women. A common misconception is that testing will identify the mutation responsible for causing cancer if it is present and that the test will only take a few days. Women, in general, give little consideration to the psychological consequences of accepting gene testing. Positive results may be distressing and might promote or hinder screening and other prophylactic practices. In some cases, they influence family planning. A negative result might lead to complacency about not developing breast cancer, which may result in non-attendance at screening [11].

Only an estimated 5 to 10% of breast cancer is inherited [12], through autosomal dominant transmission [13, 14, 15]. Women who have inherited the disease tend to be diagnosed at a younger age than cases of sporadic onset breast cancer. Genetic predisposition accounts for 33% of breast cancer cases among women less than 30 years of age [16]. However, the high prevalence of the disease (105,000 women in the United Kingdom [17]) is such that several cases could occur within the same family by chance. This is a fact not widely appreciated by the general public. A woman without any known first or second line relatives with the disease has a life time risk of developing breast cancer of 1 in 11 [14]. On the basis of a standard two child family, half of all the women in the UK will have a 1st or 2nd line relative who already has or who will develop breast cancer at some point during their life.

Elevated perceived risk and worry about developing the disease have been shown to increase interest in genetic services [12]. Once referred, the expectations of a family history consultation may include: provision of breast screening, genetic risk information, genetic testing and receipt of reassurance [6]. Only a small number of the referrals to a family history unit (approximately 5%) are eligible for genetic testing. This is because they are not at any further increased risk; the risk is insufficient for testing (less than a 25% chance of developing breast cancer [2]), they have no

living relative with the disease from whom a tissue sample can be taken, or they decline testing in favour of surveillance options. A recent study by Brain et al. (2000) amongst women "at further increased risk" of developing breast cancer reported that the majority (82%) wanted specific information pertaining to their genetic risk status, the remaining 18% either did not want specific information or they had not decided [5]. Women in the at "no further increased risk" group require information to explain why they are at no further increased risk than the general population but also to allay any residual fears they have about developing breast cancer. Hence, the presentation of genetic risk information to women has to strike a balance between those who want specific information and those who do not.

This study aims to identify the language preference for phraseology of lifetime and age specific risk of developing breast cancer among asymptomatic women, which will facilitate understanding and relieve anxiety.

II. METHODOLOGY

An information pack given to women contains a lot of information pertaining to the risk of developing breast cancer. This information might be presented from two perspectives, one of which is positive (e.g. 10 out of 11 women will not develop breast cancer during their lives) and the other negative (e.g. 1 in 11 women will develop breast cancer at some point during their lives). The sample constituted volunteers from six geographical locations within the United Kingdom (Coventry, Birmingham, Nuneaton, Nottingham, Oxford and Derby). Recruitment was via email, posters, mail shots, and family and friends network.

Each woman was asked to state her preference between positive and negative wording of the lifetime risk, and between three alternate ways of phrasing age specific risk (Percentage, Ratio and Description). The effect of order of presentation of the statements was balanced using six different orders generated according to a modified Latin Square design [17] (see Table 1). Women were randomly assigned to one of the six orders, with stratification by two age bands: 18-30 and 31-54 years.

Women's preference for the positive or negative wording of lifetime risk and the different wording of age specific risk was assessed through self-completed questionnaires, which participants returned in prepaid envelopes. The questionnaire also included demographic variables (e.g. age, marital status).

TABLE I
MODIFIED LATIN SQUARE
O = Odds, P = Percentage, D = Description

Order	1	2	3	4	5	6
Order 1	+	-	O	D	P	
Order 2	+	-	P	O	D	
Order 3	-	+	D	P	O	
Order 4	+	-	D	O	P	
Order 5	-	+	P	D	O	
Order 6	-	+	O	P	D	

A. Sample Size

Literature searches did not identify previous data on which a sample size calculation could be based. Therefore, the sample size was estimated to detect a moderate effect size of 0.5 with 80% power and significance level 5% [19]. This produced a sample size of 128; 175 questionnaires were distributed to allow for attrition.

B. Data Analysis

Quantitative data were analysed using the Statistical Package for the Social Sciences (Version 9). Appropriate summaries of respondent characteristics have been computed. Mann-Whitney and Kruskal Wallis tests were used to assess independence of voting pattern with respect to median age for lifetime risk and age specific risk, respectively. χ^2 tests were computed for the association between marital status and voting pattern, and the effects of order of presentation of the different statements. The percentage of women responding to each option was analysed using χ^2 Goodness of Fit tests. All statistical tests were performed at 5% significance level. Percentage preference and associated 95% confidence intervals were calculated for each statement.

III. RESULTS

One hundred and thirty seven completed questionnaires were returned out of 175 distributed, giving a 78% response rate. Women were aged between 17 and 55 years, with a median age of 42 years; 94% had some educational qualifications (for example GCSEs); 98% were white European; 68% were married or living with a partner; and 85% were in paid employment (full time or part time). Examples of occupations are cleaner, administrator, care assistant, researcher, managing director and health psychologist.

There were no significant differences in median ages across the different voting preferences for either lifetime risk (median age 41, 42 years for negative and positive wording respectively; $z = -0.716$, $p = 0.474$) or age specific risk (median age 42 years for each option; $\chi^2 = 0.165$, $p = 0.921$). There were no significant differences in marital status across the different voting preferences for either lifetime risk (66%, 67% of women who selected the negative and positive wording were married or living with a partner; $\chi^2 = 0.03$, $p = 0.858$) or age specific risk (69%, 67%, 69% of women who selected Odds, Percentage and Descriptive wording were married or living with a partner; $\chi^2 = 0.04$, $p = 0.982$). There was no significant association between voting pattern and the first statement presented (lifetime risk: $\chi^2 = 0.00$, $p = 1.00$; age specific risk: $\chi^2 = 4.46$, $p = 0.347$).

Negative phrasing of lifetime risk was preferred by 24% of women compared with 76% who preferred the positive phrasing. This difference was statistically significant ($\chi^2 = 36.57$, $p < 0.0005$). With respect to age specific risk, 44%, 19% and 37% of women preferred the Odds, Percentage and

Description wording, respectively. There was a significantly lower proportion of women who preferred the Percentage option ($\chi^2 = 12.82$, $p = 0.002$). The 95% confidence intervals for the proportion of women voting for each option are displayed in Fig. 1.

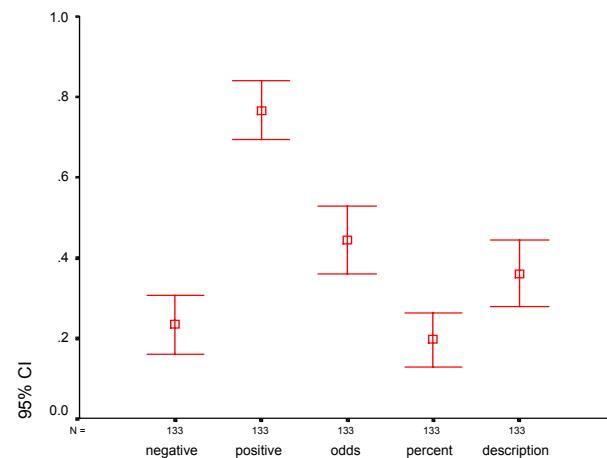


Fig. 1. 95 % confidence intervals for the proportion of women voting for each option

Key:
 Negative and positive wording refers to lifetime risk.
 Odds, percent and description refer to age specific risk.
 The boxes represent the proportions of women voting for this option and the lines represent the 95% confidence intervals.

IV. DISCUSSION

The ability to rationalise life altering information may be facilitated by the angle from which it is delivered. The findings from this research demonstrate that a significant proportion of women in the sample prefer risk communication to focus on the positive interpretation of results. Positive phraseology lends itself to an optimistic perspective and optimism implies that there is hope. The element of finality to the information is diminished and this may lead to a reduction in the perceived level of risk. Once information seems more manageable the situation is less threatening and this allows control and rationality to return.

The quantification of risk is a more complex issue. Research by Brain et al. [5], showed that the majority of women wanted risk information to give specific details about the chance of developing breast cancer. When presented with such information from three decreasingly technical perspectives, a significantly lower proportion of women in the sample opted for the most technical explanation. This may reflect the comprehension levels within the sample but this is unlikely as 94% had some educational qualifications. Alternative explanations could include the fact that high anxiety leads to a temporary decrease in comprehension ability or that numerical representation of risk may be intimidating for the reader. The remaining two descriptions were selected with equanimity. For those women who liked

the presence of statistics the ratio option provided a balance between technical information and descriptive wording. For women who did not like the statistical representations of risk the description option was applicable.

Several limitations to the study need to be mentioned. Firstly that the sample did not accurately represent the ethnic diversity of the sample attending for risk assessment. The authors are attempting to address this situation by repeating the study using a translated questionnaire in a sub sample of ethnic minorities. This would allow for greater generalisation of finding. Secondly, that 94% of the sample had educational qualifications and only 6% did not. The inability to recruit women with a lower educational status may result in the information being incomprehensible to this proportion of women. Further research into this area is required. No attempt was made to identify reasons for non-response or to determine the characteristics of this sample of women. This is an area that is being explored in the next phase of the research.

V. CONCLUSIONS

Positive phrasing of lifetime risk and ratio and descriptive wording of age specific risk were chosen as the terminology of choice by women in the sample of asymptomatic women. This information has been used to develop a literature intervention for women who perceive themselves to be at increased risk of familial breast cancer. This literature intervention is currently being evaluated in a randomised controlled study.

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